

# Developing an Infrastructure for Bereavement Outreach in a Maternal-Fetal Care Center

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Perinatal loss · Bereavement outreach · Fetal care · Maternal care · Parental grief · Grief support · Birth defects · Congenital anomalies

## Abstract

Although bereavement programs are a common element of palliative medicine and hospice programs, few maternal-fetal care centers offer universal bereavement outreach services following perinatal loss. In this article, we describe the implementation of a bereavement outreach program at the Center for Fetal Diagnosis and Treatment at the Children's Hospital of Philadelphia. The four primary goals identified when developing the bereavement outreach protocol included: (1) centralize communication for patient tracking when a perinatal loss occurs, (2) provide individualized and consistent resource support for grieving patients and families, (3) identify strategic outreach points throughout the first year post-loss, and (4) instate programmatic improvements in response to feedback from patients and their families. Strategies for establishing standardized follow-up protocols and operationalizing methods to address outreach initiatives will be shared, with the primary aim of providing other fetal care centers with a proposed model for perinatal bereavement outreach services.

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## Introduction

Each year in the United States, more than one million fetuses die before birth [1] and 4 in 1,000 babies die in the first 28 days of life [2]. Studies have shown that losing a child has a greater negative impact on both the mortality and psychosocial outcomes of the bereaved than any other type of loss [3, 4]. The significant sequelae experienced after perinatal loss highlight the need for ongoing care and resources targeted specifically for grieving parents and families [5].

Both hospital staff and bereaved families find comfort in continued contact after perinatal loss as demonstrated in prior studies [3]. For some parents, the hospital may represent the location where they received the notification of their pregnancy loss or where their critically ill baby lived and died either on a labor and delivery unit or in a neonatal intensive care unit (NICU). Hospital-based bereavement outreach programs give staff the opportunity to follow up with grieving parents, to assess for emotional risks and complicated grief reactions as well as con-

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nect them with additional supportive services and community resources, if needed [3, 6]. Ongoing contact with bereaved parents, including evaluations and forums for feedback about the patient and family experience while in the hospital, also provides clinical teams with critical insights into methods to improve patient care [6].

Although bereavement programs are a common element of palliative medicine and hospice programs, few maternal-fetal care centers offer universal bereavement outreach services following perinatal loss [6]. It is imperative that high-risk maternal-fetal care centers implement standardized bereavement outreach protocols as women carrying fetuses with congenital anomalies are at a heightened risk for perinatal loss [7, 8]. The available literature advocates supportive services for bereaved parents (e.g., follow-up meetings and/or telephone calls, sending condolence cards, etc.); however, the specific content of a bereavement program and the methods of outreach implementation remain vague in terms of who should be providing the services and the length of time these services should remain available post-loss [9–11]. In this article, we describe the implementation of a bereavement outreach program within the Center for Fetal Diagnosis and Treatment (CFDT) at the Children's Hospital of Philadelphia (CHOP), with the aim of providing other fetal care centers with a proposed model for perinatal bereavement outreach services.

### **CFDT Perinatal Palliative Care and Bereavement Program**

The CFDT is a high-risk maternal-fetal diagnostic and therapy center dedicated to mothers carrying fetuses with known birth defects that require fetal surgery prior to birth, immediate neonatal surgery, and complex neonatal treatment shortly after birth. Out of the 1,200 annual new patient evaluations completed at the CFDT, approximately 450–500 select cases necessitating specific delivery planning or immediate evaluation or intervention after birth will be born on The Garbose Family Special Delivery Unit (SDU) each year. The SDU is the world's first labor and delivery unit located in a free-standing children's hospital that is dedicated to caring for healthy mothers of babies with known birth defects [12]. Of the patients seen for an initial maternal-fetal medicine (MFM) evaluation, approximately 14% will experience the loss of a pregnancy or the death of a child prior to the first year of life.

In 2012, initial philanthropic resources were acquired to implement the CFDT's Perinatal Palliative Care and

Bereavement Program. This program formalized the provision of standardized grief services, clinical support, and bereavement outreach for all CFDT patients experiencing a loss in pregnancy or within the first year post-birth [13]. Four primary goals were identified when developing the bereavement outreach protocol:

- 1 Centralize communication for patient tracking when a perinatal loss occurs
- 2 Provide individualized and consistent resource support for grieving patients and families
- 3 Identify strategic outreach points throughout the first year post-loss
- 4 Instate programmatic improvement in response to feedback from patients and their families.

The strategies utilized to achieve these goals are described below.

### **Centralized Communication**

Identifying our target population was critical prior to program implementation. The team determined that all patients seen for an initial MFM consultation at the CFDT would be eligible for bereavement outreach services. Individuals who had a perinatal loss that occurred prior to the initial consultation and those who had never had an initial prenatal consultation did not fall within our target population. In order to create a comprehensive bereavement outreach protocol, the team developed a method to streamline communication in order to capture accurate bereavement data. There are a variety of methods used at CHOP to alert the bereavement outreach team to a perinatal loss. MFM providers are frequently contacted by referring community providers. Fetal therapy nurse coordinators are often the primary points of contact for referring obstetric offices or community NICUs when a death occurs. Genetic counselors may be notified by the hospital pathology department when they receive the deceased for an autopsy. Social workers and advanced-practice providers may be present when a neonatal loss occurs on the delivery unit or in the NICU environment. Upon confirmation of a bereavement notification, staff send an e-mail to the CFDT clinical psychologist and the resource coordinator which activates the bereavement outreach protocol (described below).

To help support the CFDT's Perinatal Palliative Care and Bereavement Program outreach efforts, the role of the resource coordinator was created. The resource coordinator is the key person for tracking all perinatal losses experienced by CFDT families and documenting them

into the program's online REDCap<sup>®</sup> (Research Electronic Data Capture) database, a secure, Web-based application designed to support data capture for research studies [14]. Once the staff e-mail is received confirming a bereavement notification, the resource coordinator inputs patient demographic information, fetal diagnosis, type of loss (e.g., intrauterine demise, selective reduction, or neonatal demise), and the location where the death occurred (e.g., the SDU, NICU, cardiac ICU, and/or outside the hospital) into the REDCap<sup>®</sup> database.

### Consistent Resource Support

In order to validate and help guide patients through the difficult thoughts and feelings experienced in response to a perinatal loss, the members of the CFDT team developed several informational packets tailored to specific types of losses [15]. These packets are written for a 6th-grade reading level and are available to families in both English and Spanish. For example, when parents experience an intrauterine fetal demise (IUID) during a CFDT prenatal care visit, the MFM physician and/or fetal therapy nurse coordinator provides the patient and her family with a packet that describes the process and options at birth, memory-making at the time of birth, autopsy and genetic testing, managing grief, physical and emotional recovery, funeral planning, talking with siblings, subsequent pregnancy after a loss, and specific pregnancy loss books and online resources for both adults and children. If a patient chooses to give birth on the SDU following an IUID, she and her family are supported in developing a supportive birth plan and are provided with additional grief resources in the postpartum period.

An additional informational packet was developed to support those patients and families who carry a fetal diagnosis of complicated monochorionic twins. Depending on the severity of the diagnosis, some parents may face the difficult decision to perform a selective reduction of one fetus for the viability of the other. The MFM physician and/or fetal therapy nurse coordinator provides these parents with a packet specifically to address the complexities of a selective cord occlusion procedure. Contents within this packet include: procedure and postoperative instructions, managing complex grief, connecting with the surviving co-twin, talking with siblings, support for the remainder of the pregnancy and preparing for birth, and additional complicated monochorionic twin resources.

Patients who experience a perinatal loss prior to or soon after giving birth on the SDU receive a special "Com-

fort Kit" from the nursing staff. The purpose of this kit is to acknowledge the parents' loss while also reminding them of the importance of good self-care in the postpartum period. Items included in the kit are: non-caffeinated tea and a mug, a journal and pen, relaxation music, mints, a lavender-scented eye mask, and additional literature on physical and emotional healing post-loss. Parents are also informed that a staff member will reach out to them by phone in the days ahead, unless they state a preference to not receive further contact from the team [9]. A condolence card is initiated by the SDU nurses, signed by the staff that worked with the patient and her family, and is mailed home within a week after the loss. The resource coordinator is integral in making sure that the staff have access to informational packets, bereavement literature, Comfort Kits, and condolence card materials, and also in proactively sustaining the inventory of supplies for the team.

The fetal therapy nurse coordinator, social worker, or clinical psychologist will make the bereavement outreach follow-up phone call one week post-loss. Using clinical judgment and knowledge of the patient and family situation, staff may make recommendations for bereavement care based on known or identified risk factors [6]. The outreach protocol includes waiting at least one week to make phone contact with the family after an IUID or neonatal demise. This timing allows the patient and her family the opportunity to transition back home from CHOP, address funeral arrangements, and communicate events to additional family members. The fetal therapy nurse coordinator also provides an outreach phone call to all families who experience a selective cord occlusion procedure. This phone call is made strategically around the time of the estimated delivery date (approximately 3 months after the selective reduction procedure). The purpose of the call is to assess the status of the surviving twin, explore any prenatal and/or postnatal complications (e.g., premature birth, NICU course, etc.), and identify any emotional or physical health risks for the postpartum mother, her partner, and the family.

### Identifying Outreach Points

The literature reports grief as "most intense during the first year post loss" and recognizes that a period of one year is considered "the norm for bereavement follow-up" [3]. Considering that 14% of our CFDT patients experience a loss each year, the REDCap<sup>®</sup> database system has been instrumental in formalizing a structure for consis-

tent outreach at three touch points throughout the first year post-loss. For every perinatal loss documented, three handwritten condolence cards are sent over the first 12 months post-loss, unless a family specifically states that they do not wish any further contact from the team. Comforting words with personalized messages are written on each card, and the contact information for the CFDT clinical psychologist is enclosed in case additional resources are needed. As we tracked patient correspondence in response to our bereavement outreach efforts, we found that parents appreciated that the team remained in contact throughout the first year post-loss, and that we still remembered their loss at the one-year memorial. Here are a few comments from families in response to outreach cards:

“The cards are great. It is a simple reminder that someone cares, that we are not alone in this journey.”

“Just wanted to let you know we received your card a few weeks ago. Thank you for keeping us in your thoughts, we really appreciate it. We are all doing ok, some days better than others, but that’s expected.”

“We got the card you sent in the mail today. Thank you for thinking of us still. It’s hard to believe it’s been a year, and it’s been quite a long and difficult year. We have come a long way, but there is definitely still a long road ahead.”

“We just got your kind sympathy card. Thank you very much. It’s nice to still get cards 6 months after the loss. In fact, on purpose from now on, I’m waiting a few months to send sympathy cards because it’s nice to know that people are still thinking of you.”

“Thank you so much for the card you sent on [our daughter’s] 6 month anniversary, it meant a lot to us. There isn’t a day that goes by that we don’t think of our [daughter] and all the lovely people who helped us at CHOP. Every day we are building strength. Sometimes it feels like slowly, but surely.”

Both fetal and neonatal losses are addressed using the same outreach protocol. Cards are sent at 1 week, 6 months, and 1 year post-loss. For families experiencing loss through a selective cord occlusion procedure, the first card is sent two weeks post-procedure after the ultrasound follow-up visit has confirmed the healthy status of the surviving twin. If a dual demise occurs, then both losses are accounted for in the database and the content of the condolence cards is adjusted accordingly. Additional outreach cards are sent three months post-procedure, which usually falls within the same time frame as the birth of the surviving twin, and another card is sent 12 months post-procedure.

The calendar application within REDCap<sup>®</sup> alerts the resource coordinator when a 1-week, 3- or 6-month, or 1-year card is scheduled to be sent. A monthly report, which tracks all bereavement data, outreach correspon-

dence, and patient feedback, is disseminated to the treatment team. The resource coordinator also records when correspondence is received from families in response to the team’s outreach efforts, which may include memorial service highlights, sibling and family responses, subsequent pregnancy announcements, or words of gratitude to the care team. Receipt of bereavement outreach cards often triggers patients or family members to ask for additional grief resources, and, in these cases, the resource coordinator assists the social worker and clinical psychologist in providing families with lists of appropriate community therapists, local grief support groups, and online resources.

### Programmatic Improvement

For patients and families who experience a perinatal loss and give birth on the SDU, the resource coordinator sends out an online REDCap<sup>®</sup> bereavement survey at the one-year memorial of their loss. The survey link is sent to both the patient and her partner, requesting their feedback on the obstetric care received in addition to updates on their physical and emotional coping after being discharged from the SDU. Parents are asked to complete the survey that consists of 18 open-ended questions and two quantitative measures, the Grief Evaluation Measure and the Adult Attitude to Grief Scale. Obtaining insights from parents, while continuing to develop better ways to increase response rates to surveys, is essential for program evaluation and quality improvement [9]. Bereaved parents play an instrumental role in teaching our team about effective clinical and outreach practices. All patient correspondence and survey data are collected and used to formally assess the value of the specific components of the bereavement outreach program (e.g., informational packets, condolence cards, phone contact, etc.), and this helps our team to get a glimpse into the grief experiences of our patients and families [16]. In addition, bereaved parent participation in quality improvement projects has helped shaped our program’s initiatives, the timing of bereavement outreach, and the supportive services offered [9]. For example, here are a few survey comments that identified targeted areas for future intervention and support:

“I think it would have been good to focus on the ‘after,’ perhaps even a session or two postpartum.”

“My 6-week postpartum visit was tough. Our doctor back home really didn’t know how to respond, so it was rather awkward.”



“The loss of one of our twins was not recognized by my work as a bereavement.”

“In men, grief is often a delayed reaction, this was especially true in me. At the six month point, I felt a wave of deep grief. The first six months I was just trying to push through and make sure my wife was ok.”

After one year, all families followed by the CFDT Perinatal Palliative Care and Bereavement Program transition to the CHOP Evenstar Program, as this program continues to provide long-term grief services for families in need. It also hosts institution-wide memorial events three times a year. These gatherings are designed specifically for bereaved families, both those who have experienced a perinatal loss or the death of an older child cared for at CHOP. The goals of the events are to offer families an opportunity to reconnect with CHOP staff, share memories, and honor their child’s legacy. Families are encouraged to send in a picture and brief story of their child for the “memorial book” and slide-show presentation. Remembrance activities include a photo memorial of all children, members of CHOP staff reading out the names of the deceased, music, and quiet moments of reflection. The program also enables older siblings to participate in legacy-building activities and connect with other bereaved siblings. Since the initiation of the CFDT Perinatal Palliative Care and Bereavement Program, there has been a noticeable increase in CFDT families present at the memorials. Families find comfort in returning to CHOP and reconnecting with the team. Here are a few quotes from families who have attended the memorial services:

“I’m most appreciative that CHOP has this memorial every year. I appreciate the opportunity to grieve the loss of my son at the place where he passed. And, to have staff there who knew my son!”

“Knowing that our son hasn’t been forgotten means a lot. Even though he was only here for three days, you are helping us to remember that he deserves to be remembered. You have no idea how special that is to us.”

“I’m grateful to hear my daughter’s name and see her face in the slide show. For those of us who are pretty far out from our loss, we don’t hear their names as often as we used to. So just hearing her name read aloud means a lot.”

## Conclusion

The primary goal of a perinatal bereavement outreach program is to promote effective grief support services through close patient and family follow-up. As each parent experiences grief differently, developing a

comprehensive program that covers the various forms of grief can be challenging. However, as a first step, bereavement programs should connect grieving patients and families to helpful written and online resources that provide information about what to expect in the weeks and months ahead after experiencing a loss, the signs of typical and complicated grief, when to seek out mental health services, strategies for establishing a daily routine, focusing on sustaining good self-care, and maintaining social connections [6]. Based on the feedback received, our patients and families benefit from receiving outreach support over a 12-month period [17]. With ongoing assessment and outreach from the team throughout the first year post-loss, our hope is to prevent the development of complicated grief and psychological illness for our patients and their families [6]. Bereavement outreach helps grieving parents adapt to change after a loss and to integrate the loss into their personal narrative [6, 18].

Developing an infrastructure for communication within the team, garnering buy-in from key institutional stakeholders, establishing standardized follow-up protocols, and operationalizing methods to address outreach initiatives are fundamental to the success of the program. Recognizing that perinatal loss is an additional risk factor for postpartum mood and anxiety disorders [18–20], we encourage fetal care centers to implement a standardized perinatal bereavement outreach program as part of routine care. Fetal care centers are primed to follow pregnant patients closely due the heightened risks throughout the perinatal period. Therefore, follow-up supportive services and referrals to grief resources provided by the same team throughout the postpartum period [17] are critical to help patients and families navigate the many challenges that arise after a perinatal loss.

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## Statement of Ethics

The outreach protocol discussed in this paper was approved by the CFDT Research Committee (jatresj@email.chop.edu). This is not a study involving human subjects; therefore, no institutional review board submission was deemed necessary.

## Disclosure Statement

The authors have no conflicts of interest to disclose.

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## Author Contributions

J.C.M.C. developed the outreach protocol, conducted the literature review, the draft of the article, the critical revision of the article, and the final approval of the manuscript prior to publication. A.B. co-wrote the manuscript, conducted the literature review, edited the draft, and sustained the REDCap<sup>®</sup> bereavement database for data analysis. L.J.H. and J.S.M. conducted the critical review of the manuscript prior to publication.